

Keynote 2013 WRAP Summit in Philadelphia

Delivered by Jane Whitaker/Winterling, Friday September 13, 2013



Usually Mary Ellen does this sort of thing and she does it so beautifully but she decided she had to retire and so as one of the founding people I am both terrified and honored to be here.

I would like to talk about 3 things today. My past and how I came up with the idea of WRAP. How that simple structure came to have the larger structure that has allowed many others to facilitate WRAP which in turn allowed WRAP to become an evidence based practice **and** what I see and hope for in the future.

So I am a baby boomer. The oldest of 5, I was born right after WW II into a small farming village in NYS and a culture of keeping secrets. Independence and strength were to be cultivated and problems were better left alone. I am sure many of you in this room can identify with what that must have been like for those veterans struggling with PTSD alone. My favorite uncle got sick and I was not allowed to see him, after his death I found out he had had cancer and they did not want to upset me and my siblings because he did not look healthy. We did not discriminate any problem went into the closet.

As a kid I had big hair, thick and long and I had huge energy. Needless to say I did not fit in to this reserved community and I learned from all this that to keep myself and my family safe I needed to become invisible and disappear just like so many other people did in the community. No one knew there was such a thing as Mental Health Challenges. People just disappeared or drank. Now we call it isolating and addiction. After my first child was born I went through a particularly dark time. A friend told me about an abandoned house in New Hampshire and I got permission from the owner to live there in return for paying the taxes on the place which were very modest. I disappeared there for 4 years.

As I was starting to come out of my shell I met someone who said you need a job and so do I so let's go job hunting together. We found work at the Brattleboro Retreat a private psychiatric hospital. My mouth was open for the first year in amazement. I began to realize that many of the people from my community including myself were struggling with MH issues that were never treated **and** that being a staff member is a great place to be invisible. We used to talk about the fact that none of us had the resources to stay at the hospital or see a therapist if we needed it. There was this myth that if you worked in the MH System you couldn't possibly have any MH Issues. Thank God we are more enlightened these days.

The hospital partnered with Dartmouth University and opened a chronic pain unit I applied and was transferred. All of a sudden there were psychologist's coming out of the woodwork with all these ideas and wanting to know if they would work. The long and short of it is that I quickly

realized that the big difference between the chronic pain unit and MH units were expected outcomes. People on both units had very similar problems but were treated very differently. If you had chronic pain you could learn to manage and have a life if you had MH issues you were just chronic.

On the chronic pain unit the psychologists would come out of their offices and say to us MHW's, we want to see if the way people communicate has any impact on their pain so develop a communication class and we can research it. Let's have them journal so we can tell what is impacting their pain and here's some ideas. Because I was part of developing all of these tools, I was learning a huge amount and applying it to my own life. I learned how to pace myself and that I had to spend my energy wisely, communicate differently become a subjective observer of my own thoughts, feelings and behaviors vs. just reacting to them. People would come spend 6 weeks with us get off pain meds, get their pain to a manageable level leave and be back in 3 weeks wondering what they had done to feel better and have to start all over again.

After 17 years I burnt out, left the hospital, took some time off and when it was time to find another job I went to work for our local Community MH agency, it was while working there that I met Mary Ellen. She had been hired by the state of VT to provide 3 MH Recovery Workshops one of which was in Bradford Vt. Because we were all local we decided to travel together. I was the driver, she was the passenger and the back seat was full as well. We left at 7:30 am and got back at 6pm. The days were long and the conversations rich and interesting. It was Mary Ellen's willingness to be so open about her own experiences that gave me the courage to admit even to myself the depth of my struggles. When Jesse Parker stood up on the last day of that workshop and said "This all sounds great but I can't make it work in my life" I knew exactly what she was talking about. This was something I had heard over and over again from people dealing with all kinds of challenges from all walks of life. They hoped the sky would open and somehow wellness would fall like rain, they just did not know what else to do.

On the way home that day I began to talk about what I had learned on the chronic pain unit and applied to my own life, and as a result had come up with a way to take care of myself that had worked for more than a decade. Mary Ellen asked me to present these ideas at our day long follow up session and that is what I did. These ideas were certainly not as beautifully organized as they are today because I had never thought about them as something to pass on to others but Mary Ellen saw something and began to work with them in her own life and talked with me and many others who were willing to try to organize their wellness using these ideas. I knew from personal experience that we had to write it down or we would lose our hard work if we experienced a period of wellness and then things started to slide down hill, so I was very adamant about this. Notebooks seemed the easiest and cheapest place to start developing our plans, and because we were pioneers we knew we had to be fully involved in creating our plans ourselves, that no one else could do this for us, and in supporting each other in the undertaking we were up to the challenge.

Mary Ellen who was starting a career as a speaker and educator realized how much this spoke to people and was needed. People often responded to her at the end of a presentation in those early days with "finally something I can do to help myself". Because of these kinds of responses she came to me and we put our heads together. I wrote up the definitions in the Red book and added more to

the definitions in Winning Against Relapse, Alan McNabb came up with the title WRAP and it was off.

Of course once you take something on the road things come up that you never expect. WRAP was so simple that it totally threw some people and Mary Ellen and I had long conversations about modifying or changing the names of the different sections. What I am like when well was added to the DMP early on and of course the Post Crisis Plan was added much later but the Plan has stayed essentially the same as it was that first day. We felt that this was what naturally evolved out of the conversations and work of people who would actually use a plan and changing it would amount to us trying to make it better until it was useless.

Culture statement

That being said each of us personalize our plans in ways that make sense to us – Mary Ellen’s TBD is Things going to hell in a hand basket, for me I think of Trigger as potholes. But when we came together as a group the Section Titles and definitions in the Red Book gave us a common language with which to have conversations. I really feel that it is because of the simplicity of the language that WRAP has gone so far. **You** can take it and make it **your** own and make it work for **you**. It crosses the barriers of language, culture and challenge for this reason but when we facilitate or speak to a group we must use our common language and understanding of these concepts. These concepts and language are the trunk of our tree and while our branches may blow in the wind the trunk remains solid and true.

Mary Ellen quickly realized she was not going to be able to spread this by herself. I had 2 adolescent girls at home who needed me to be there and Allan was willing to do some training but realized that to maintain his wellness his ability to be on the road was limited.

The Facilitator Training was born. Again this came from responding to a need.

VT and NH had the first facilitator trainings and they were held at about the same time. I was in the first Vt. facilitator training and co-facilitated the second one with Mary Ellen. These were similar to and yet different from the trainings of today. As you know if you take a Seminar 1 you are qualified to take Seminar 2 and facilitate. This has not changed since the beginning. Many people who took those early trainings had never done anything like facilitating, we called it teaching then, in fact for many this was their first job in a long time, and people like me who had done educational trainings had never self-disclosed and saw trainings through a system lens even though we were peers. **What a mess.**

I know there were days that Mary Ellen could not answer the phone and listen to one more complaint from either facilitators or those who were sponsoring them, but we believed so strongly in WRAP’s ability to change people’s lives that we struggled on. Many of us took the Facilitator Training and felt we needed more so Mary Ellen started mentoring people and held regular Refresher Trainings in those early years. The Refresher Trainings were the place where we came together as facilitators to talk about and problem solve issues we were facing. This was when the Values and Ethics of WRAP became a critical part of WRAP and the facilitator training. The Values

and Ethics helped us from both sides of the fence and gave us a way to talk about differences in a respectful way and maintained our integrity as facilitators. These discussions were also where it became obvious how important it is to have a co-facilitator.

Co-facilitation is important for so many reasons and is one of the things we have fought for over and over throughout the years and these are a few reasons why.

As a facilitator I have to be willing to talk about all those things that I kept secret in a way that is helpful and limited. It takes a tremendous amount of courage and trust to do that and my co-facilitator partners with and supports me in that process.

We hold each other accountable

We support each other because this work is wonderfully creative and difficult all at the same time and if one of us is struggling the other can fill in and the work proceeds. As we shared the experiences we had both good and bad as facilitators we realized how important it was to have standards we could point to so that we could maintain the voluntary nature, integrity and accessibility of WRAP for everyone as we went out into the world.

Mary Ellen began to realize she needed to have an entity take on, hold and be available in ways she could no longer be available because WRAP had become too big and the Copeland Center was born. We are here today because of the hard work of the employees and board members of the CC so I personally want to say thank you. I also want to encourage all of you here today to become a member of the CC so we can keep it strong and able to be there for us as a resource independent from large industries like the pharmaceutical companies.

WRAP in Vermont

In 2000 I left the community MH agency. I had been facilitating WRAP workshops and I had supported someone in creating her crisis plan who had taken the workshop. She had worked so hard on her crisis plan and when she felt ready she asked me to make arrangements with someone from the crisis team so she could show them and talk to them about her crisis plan. The meeting was set and she started, about half way through this person stopped her and said it was great, obviously she had spent a lot of time on it, but it was too long and so they could not use it. Needless to say she was devastated and felt awful. I did too and realized I had come to the end of the road working from within the system. I took a job working for the only peer agency in our state VPS. It is a very small agency, when I started I was person no 5 to cover the whole state but what a blessing, less money but much happier. I got to work coordinating and facilitating WRAP all the time and when I wasn't doing that I was advocating in the system for change.

WRAP has been a part of VT since 97. It started with grants and the state hoped when the grants were gone the local community MH Agencies could and would continue the WRAP workshops. While there was a lot of lip service it seemed very little happened. We trained well over a hundred facilitators over the years and when it came time to find someone to facilitate it was near to impossible.

I believed then and I know now that a big problem was the lack of mentoring from experienced facilitators. Both sides needed help. For the peers self-disclosure was easy but maintaining the structure of the group was difficult. For staff members even if they were peers self-disclosure was very difficult and in many cases staff were told it was not ok.

Ummmm WRAP requires that you be able to do both well. If opportunities to practice and access to facilitators who have both skills are limited as well, it becomes easier to just stop which is what many people did both staff and peers.

Another problem we had was there was no infrastructure to support WRAP and by that I mean: who does the marketing, who do you call to register, who orders the supplies and food, what about confidentiality. What happened was WRAP became available to only a few from a few programs. Ugh this was not how we envisioned it.

The Future I see when I think of WRAP

People graduating from WRAP Workshops asked over and over “what now” they wanted and needed a way to continue coming together as a community to support each other in this new way of thinking and being, called WRAP. We had talked about support groups as a tool but their experience was, it felt like another type of therapy or that it was a click and they were not welcome. One more time I sat down with a small group of people and we began to develop a structure for support groups that incorporated many of the WRAP principles.

After I left the agency I continued to develop a manual. It is called Steps to Wellness: A Manual for Developing Community Supports. I strongly believe in this because I believe we need to build places where we can share leadership and responsibility for the success or failure of the support group. This continues the building of the hope and empowerment people experienced in the Introductory/Seminar 1 workshops. It is a simple structure that can be put into place so group members can share the many roles and everyone can receive support.

There will be 2 consecutive workshops today were I will go over the manual and we can practice a meeting. So I hope you will come.

In many ways the future is here in pockets all over the country and world. In the US, Health Care Reform has offered us unique opportunities. If health care is going to be cheaper we will have to change from treating problems to preventing problems and WRAP is one of the best prevention strategies I have ever known. Once you understand the underlying concepts you can apply it to anything that challenges you. **Anything**

In VT we are going to a single payer system as part of our health care reform. Because we must partner to accomplish this goal we have been given the opportunity to work with the Dept. of Health through the Blueprint Project which has the task of rolling out this single payer health care system in VT and the development of prevention or self-management programs. As the result of the successful implementation of WRAP in one of our Rural Home Health Agencies and the very impressive outcomes, Primary care Doc's started to refer people to WRAP who needed help with a variety of problems. I will never forget the woman who came and said OK I was kicked by a horse. I

can never ride again, I am in pain all the time I am depressed and very cranky but I do not have a mental illness. I agreed with her she was very cranky but she stayed for the whole workshop and at the end said WRAP had really helped her examine what was important in her life and move on to a promising future despite its being a different future than she had planned for.

As a result of outcomes like this VPS is working with Blueprint and the Dept of MH to make WRAP available to anyone in VT who wants to learn about WRAP. Again we were a small group from multiple agencies who worked closely with the Copeland Center to create an infrastructure that would build and sustain WRAP workshops and the facilitator's who facilitate them. We worked on this for many months so when we started rolling it out we had already problem solved many of the issues that would come up. We also had an advantage we had the money.

In working together as primary care and MH partners we came to realize there were many language and culture differences. When we were at loggerheads we realized we had to stop and discuss definitions of words and talk about how different our cultures were.

Writing things down, so important!

We developed an implementation guide which laid out how this infrastructure works, its 9 pages long and very helpful to everyone involved. It answers many of the logistical issues in putting together a workshop and how the infrastructure works. We are currently working on another piece of infrastructure and that is a recruitment guide. We have to have a certain number of participants to hold the workshop and some of the home health agencies are struggling with how to get the word out.

Mentoring – this is a critical piece of the infrastructure and without it I think we will fail. WRAP Facilitation is not easy it requires that one be willing to grow right along with the participants and yet be able to keep things moving and on track. It requires that you be able to use your life experiences to make this simple structure come to life. It requires the ancient skill of storytelling to illustrate the point. In VT at this time new facilitators are strongly encouraged to facilitate with experienced facilitators and I must say that for those who decided not to use the mentoring their groups usually failed and even if they did not they were on the phone quickly. Mentoring is a way to avoid many if not all of the problems new facilitators run into and it makes the workshop a wonderful experience for everyone. We are currently building this workforce. There will be ongoing opportunities to use skills learned and the standards developed to make sure we uphold the fidelity of the practice. As part of the group rolling this out in VT we have a close relationship with the Copeland Center and Matthew and Katie Wilson are amazing.

In Closing

You may have noticed that I have talked about more than MH Challenges and that is because I am more than my MH Challenges. My WRAP has carried me through the death of my sisters, thyroid disease and divorce. I have used WRAP to lower my blood pressure and given that my younger sisters died of heart attacks I knew how it might turn out if I did not take steps to deal with this issue. I know from experience that I have the strength to meet these challenges because I have a WRAP but even more importantly because I have hope and the support of so many people who I

have met on this journey. I learned that we can change our world. I learned about the power of coalitions and I learned about the invincibility of dreams.

So what have I gotten from this process? I have gone from being alone in my struggles to having a community who believes in me as much as I believe in them. I do not need to know the details of each of our struggles just knowing you that you are on the journey with me gives me courage and hope. I can fully embrace all of myself because I am much larger than my MH Challenges and what I find is I am amazingly normal and amazingly specially and different all at the same time. I get angry; I laugh, cry, worry about my family and enjoy my friends.

I would also like to thank each and every one of you in this room. You represent a prediction I made to Mary Ellen that WRAP would go all over the world and a dream that things could be very different from what they were then. It is amazing that in this short time both have come true.

BIOGRAPHY

Jane Whitaker/Winterling, Vermont Psychiatric Survivors, Grant & Education Director. Consultant to Vermont Blueprint for Health Project is one of the original group of people responsible for the idea and development of WRAP. For this reason she has the ability to bring a unique knowledge of WRAP and the history of its development that is inspiring and allows others to share in the amazing journey of how WRAP began, the people who influenced it and helped to deepen our understanding of what it means to be well thus making WRAP what it is today.

Jane has experienced both sides of the mental health system and is a strong advocate for both peers and professionals and the need to be able to reach out to each other to change things in ways that benefit us all. It was while working at a local mental health agency that she met and began talking to Mary Ellen Copeland about ways to create what became the structure of WRAP and how that structure might allow us to “make it work” in our lives.

Jane has and continues to work extensively in Vermont as an advocate and educator, using WRAP its values and ethics and her belief that recovery is possible for all, to reach people struggling with Mental Health issues, Addictions, Trauma and difficult physical conditions. She is a Master Facilitator for the Copeland Center, being one of the first facilitators trained by Mary Ellen. She enjoys nature, walking and has a tool box full of things that keep her well.